

A National Program of Cancer Registries

AT-A-GLANCE

1995



*"A network of cancer registries can be our most potent new weapon
against the disease."*

*John Healy, Chief of Orthopedic Surgery at Sloan Kettering Cancer Center, New York
Reader's Digest, June 1992*



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service



Why Do We Need a National Program of Cancer Registries?

The Burden of Cancer

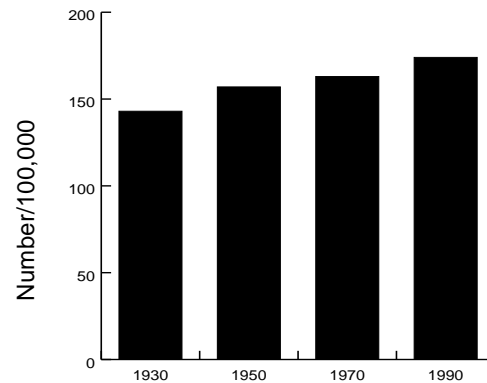
The American Cancer Society (ACS) estimates that more than 8 million Americans alive today have a history of cancer; 5 million of these were diagnosed 5 or more years ago. Most of these 5 million can be considered cured, while others still have evidence of cancer. In 1995, about 1,252,000 new cancer cases will be diagnosed. This estimate does not include basal and squamous cell skin cancers and in situ carcinomas except bladder carcinoma. The incidence of these skin cancers is estimated to be more than 800,000 cases annually. There has been a steady rise in the cancer mortality rate in the United States in the last half-century. In 1995, about 547,000 people will die of cancer — more than 1,500 people a day. One out of every five deaths in the U.S. is from cancer.

A National Prevention Strategy: Cancer Surveillance

The National Program of Cancer Registries (NPCR) serves as a fundamental tool in surveillance efforts that will provide the needed factual basis for appropriate policy decisions and allocation of scarce resources. Cancer surveillance refers to the ongoing, timely, and systematic collection and analyses of cancer incidence and mortality data crucial to the planning, implementation, and evaluation of public health practices.

"The goal of this program is to reduce cancer mortality as part of a national disease prevention strategy," said U.S. Health and Human Services Secretary Donna E. Shalala.

The age-adjusted mortality rate for cancer



Source: American Cancer Society

The final link in the surveillance chain is the application of the data to prevention and control programs — by evaluating program effectiveness and planning for the future. Statewide cancer incidence and mortality data can be used to identify trends, patterns, and variation for directing cancer control efforts, conducting research, and designing programs to reach medically underserved populations.

"The goal of this program is to reduce cancer mortality as part of a national disease prevention strategy," said U.S. Health and Human Services Secretary Donna E. Shalala. "We know that the burden of cancer for Americans varies widely by geographic location and by ethnicity. A national system of cancer registries can help us understand the disease better and use our resources to the best effect in prevention and treatment."

How Will the Data Be Used?

- As the foundation of a national, comprehensive prevention strategy.
- To monitor trends in cancer incidence and mortality.
- To guide cancer control program planning and evaluation.
- To prioritize health resource allocations.
- As a source for population-based epidemiologic research.

"The reason for collecting, analyzing, and disseminating information on a disease is to control that disease. Collection and analysis should not be allowed to consume resources if action does not follow."

Foege, William H., et al., International Journal of Epidemiology, 1976; 5:29-37

Congress Takes Action

The Cancer Registries Amendment Act

In October of 1992, Congress established a National Program of Cancer Registries (Public Law 102-515, The Cancer Registries Amendment Act). This legislation authorizes the Centers for Disease Control and Prevention (CDC) to provide funds to States and territories to enhance existing cancer registries; to plan and implement registries where they do not exist; to develop model legislation and regulations for States to enhance viability of registry operations; to set standards for completeness, timeliness, and quality; and to provide training. The enabling legislation was sponsored by Senator Patrick J. Leahy and Representative Bernie Sanders, both of Vermont.

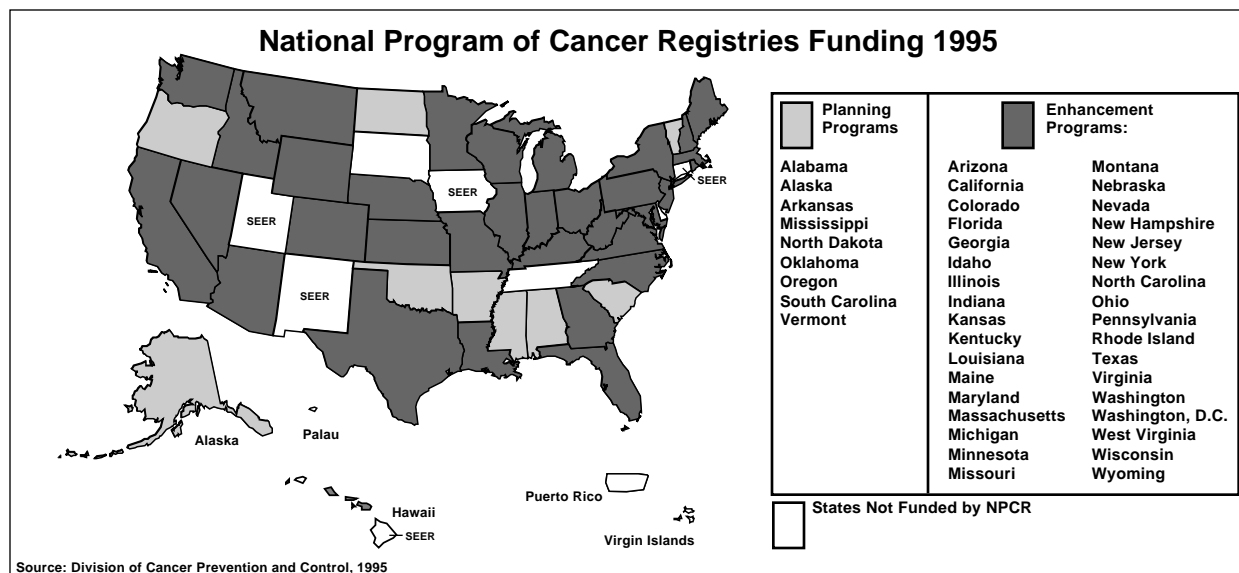
With fiscal year 1995 funds of \$17.6 million, 42 States and the District of Columbia are currently receiving CDC support for cancer registries: 34 for enhancement of established registries and 9 for developing registries where they do not currently exist.

Previous Status of State Registries

Prior to the NPCR, 10 States had no existing registry and 40 States had registries operating at some level — but many lacked the financial support and the personnel to gather complete, timely, and accurate data on 100 percent of their population or to ensure minimum standards of quality. A number of States also lacked legal support for their operations, further hindering their ability to collect necessary information.

“The success of public health programmes, whether aimed at increased vaccination coverage, reduction of alcohol consumption, or increased utilization of mammography in women over 50, must ultimately be assessed by their impact on morbidity and mortality.”

Berkelman and Buehler: International Journal of Epidemiology, 1990; 19(3):628-35



NPCR Priorities

Timely and Complete Reporting

The NPCR enables complete, timely, and standardized reporting of cancer data by age, ethnicity, and geographic region — within a State, between States, and between regions. The information collected will cover 100 percent of the State's population.

Comprehensive, timely, and accurate data about cancer incidence and stage at diagnosis are needed

to provide useful feedback for evaluating progress toward cancer control in all 50 States and the territories. Such data have not been uniformly available at the State and local levels, although numerous cancer control programs have been initiated for breast, cervical, and skin cancers, among others. The data will also aid State health departments in conducting population-based epidemiologic research.

NPCR Priorities

Computerized Data Collection, continued

The NPCR sets the stage for States to develop and implement a plan for statewide computerized data collection and electronic transmission of codes and text to the central registry. All facilities such as hospitals, therapeutic radiation facilities, free-standing surgical centers, and pathology labs are required by State law or regulation to report cancer cases. Hospitals are the reporting source for approximately 95 percent of cases in a central registry. Computerized reporting from hospitals will improve registry data quality by incorporating standard edits that can be applied to the data prior to submission. This approach allows for resolution of problems at the data source.

Quality Assurance

All central cancer registries are expected to have a section or unit responsible for quality assurance activities such as editing and reviewing data, linking and matching cases, training State personnel and hospital cancer registrars, conducting case-finding audits, and developing/maintaining written policies and procedures.

Standardized Systems

The NPCR requires each funded State to implement the standards for data quality and format as described by the North American Association of Central Cancer Registries (NAACCR) and endorsed by the CDC.

Technical Assistance

The Division of Cancer Prevention and Control (DCPC) at CDC plans, directs, and supports cancer control efforts through collaboration with prevention partners in State health agencies; Federal agencies; academic institutions; and national, voluntary, and private sector organizations.

DCPC convenes an annual meeting of funded registry states for information sharing, problem solving, and training. Site visits are scheduled as needed to assess program progress and mutually resolve problems. DCPC assists States and national organizations in using cancer surveillance data to describe State or national disease burdens, to evaluate cancer control activities, and to identify populations at high risk of certain cancers. DCPC routinely collaborates with Federal, State, and private organizations on the design, implementation, and analysis of surveillance research related to cancer.

How Does the NPCR Complement Existing Cancer Registries?

NPCR-funded central registries will complement existing registries such as the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) program. The SEER program gathers in-depth data on a sample of the population in five States (Connecticut, Hawaii, Iowa, New Mexico, Utah) and six metropolitan areas (Atlanta, Detroit, Los Angeles, San Francisco/Oakland, San Jose/Monterey, Seattle), covering about 14 percent of the U.S. population. It monitors trends in incidence, treatment, survival time, and extent of disease.

The NPCR, when fully operational in all funded States, will collect cancer incidence data on 93 percent of the U.S. population, including first course of treatment and

stage at diagnosis. The information can be used to evaluate existing cancer screening programs and to analyze cancer occurrence regionally, since cancer risk and environmental exposures often cross state lines. The NPCR will provide information to permit additional analyses on cancer as it relates to race/ethnicity.

CDC works closely with other federal agencies and with national organizations such as the NAACCR, the American College of Surgeons, the National Cancer Registrars' Association, the ACS, and other professional organizations to ensure coordination of efforts.

For more information, please contact the Centers for Disease Control and Prevention, Mail Stop K 64, 4770 Buford Highway NE, Atlanta, GA 30341-3724, (770) 488-4751.